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SHORT REPORT

Efficient Expansion of a Behavioral Survey to Assess Sex, Gender, and Behavioral Risk Among Transgender and Nonbinary Individuals: HMU! (*H*IV Prevention for *M*ethamphetamine *U*sers)

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Abstract

Transgender and gender nonbinary (TGNB) individuals are at high risk for HIV acquisition. However, TGNB individuals are often excluded from research and public health surveillance, both as participants and as reported sexual partners. This research study aimed to be inclusive, correctly classify TGNB participants, and accurately describe sex partners and sexual activity of participants to assess HIV risk while minimizing participant burden. The adaptation of survey questions designed for cisgender men to include TGNB participants and partners was feasible and relatively straightforward. However, additional work is still needed in this area to increase inclusivity and research participation by TGNB individuals. Clinical Trial Registration Number - NCT03584282.

Keywords: HIV; sexual behavior; survey instrument; transgender research

Introduction

Evidence suggests that transgender and gender nonbinary (TGNB) individuals are at high risk for HIV infection. One meta-analysis estimated HIV prevalence among U.S. transgender women to be 14.1%, highest among black (44.2%) and Latina (25.8%) transgender women.[1] In transgender men, prevalence was 3.2%,[1] but transgender men who have sex with men (MSM), who are at significant risk for HIV acquisition, were not distinguished from those who have sex with women. Studies of gender nonbinary individuals are even more limited,[2] although initial research suggests that gender nonbinary individuals have distinct sexual practices and networks from binary-identified transgender individuals; a systematic review found insufficient data to estimate HIV prevalence.[3]

One challenge is the frequent misclassification of TGNB individuals that occurs in clinical care, research, and public health surveillance. Until recently, most systems have collected sex/gender data as binary, and the National Institutes of Health still requires binary data in research enrollment reports.

A second challenge is the historical exclusion of TGNB individuals from research. Consequently, guidance on the use of HIV pre-exposure prophylaxis (PrEP) is limited because of lack of data.[4] TGNB individuals have also been excluded from large-scale public health surveys used to monitor HIV in key populations and generate data to inform policy and funding priorities.[5] The National HIV Behavioral Surveillance (NHBS), one such project, has traditionally excluded TGNB individuals from two of three cycles; however, a new survey of transgender women (NHBS-Trans) was implemented in 2019–2020.[6,7]

Misclassification and exclusion disregard gender identities of patients and research participants, limit understanding of how pharmacologic and behavioral interventions affect these populations, and perpetuate

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disparities. Unlike for cisgender MSM, there are no standardized survey instruments for assessing sexual history for TGNB individuals. The Hit Me Up (HMU!: HIV Prevention for Methamphetamine Users) Study (NCT03584282) was designed to evaluate the impact of text messaging and peer navigation on PrEP adherence and persistence among persons who use methamphetamine.[8] This report will focus on adaptation of the study protocol and survey questions for TGNB participants and sex partners.

Methods

Study team

The research team included three staff members (one who was TGNB) with experience working with MSM and TGNB individuals. A Data and Safety Monitoring Board (two community advocates for transgender populations and persons who use methamphetamine, a statistician, and a substance use researcher) provided guidance on the protocol, recruitment procedures, and community engagement.

Approach

The HMU! survey included questions about sexual health, mental health, substance use, PrEP adherence, and stigma. Brevity (< 20 min) was critical based on advice received from community collaborators that participants who use methamphetamine would not complete an extensive online survey. The team used validated scales where possible and developed questions by adapting past work and relevant surveys, including the HIV Incidence Risk Index for MSM (HIRI-MSM) Score[9] and Project DETECT,[10] based on the NHBS survey instrument.[11,12] The HIRI-MSM Score[9] was used to assess HIV risk because, as mentioned above, we were unaware of any validated risk score inclusive of TGNB individuals.

Sex assigned at birth and gender.

At the Public Health—Seattle and King County STD Clinic (now called the Sexual Health Clinic), changes to the intake form to a two-question assessment (sex assigned at birth and current gender identity) increased the proportion of clients classified as transgender and gender nonconforming from 0.5% to 2.4%.[13] HMU! used this pattern, expanding gender options further. We were advised by community partners to use "sex assigned at birth" and not "sex at birth" or "biological sex," to ask about gender directly and not how people "consider" themselves (implying that identity is chosen), and to not use "other" to prompt write-in responses (which might lead to stigmatization associated with "othering").

Introduction to behavior questions.

Each survey section had a short introduction. For less-sensitive topics (e.g., concomitant medications), this was one sentence. However, because prior work had identified high levels of stigma in the study population around sexual behavior and substance use,[14] these introductions provided more context and emphasized the lack of judgment. This was considered critical to justify potentially triggering questions and minimize risk of stigmatization.

Assessing risk for HIV acquisition.

Risk questions had two important components: sex partner gender and type of sexual contact. Assessing sex partner gender is important because some populations (e.g., cisgender MSM) have higher HIV prevalence than others. Similarly, sex acts carry different risks of transmission,[15] with highest risk for HIV acquisition associated with receptive anal intercourse followed by insertive anal, receptive penile-vaginal, and insertive penile-vaginal intercourse. The HMU! team aimed to focus on the highest risk exposures.

The strategy used in the most recent cycle (NHBS-MSM5) asks sexual contact questions twice: once about oral or anal sex with partners who are "men" and then about vaginal or anal sex with partners who are "women" without specifying whether partners are cisgender or transgender. This structure poses a challenge for participants with transgender partners, reported by 9.3% of participants in prior work with this population.[16] Expansion of this format to distinguish TGNB sex partners could potentially double the survey. Instead, as brevity was the goal, participants were asked a single set of sexual history questions about all partners.

HMU! adapted terminology reflecting how TGNB individuals talk about their bodies, avoided defining sex for survey participants, and tried to remain nonjudgmental about sexual practices. NHBS-MSM5 begins this section by defining what sex is:

> "For these questions, "having sex" means oral, vaginal, or anal sex. Oral sex means mouth on the vagina or penis; vaginal sex means penis in the vagina; and anal sex means penis in the anus or butt."

Based on their experience working with TGNB clients, study staff decided this could be problematic

for participants who use different language to identify body parts or engage in other activities they consider sex (e.g., penetration with a dildo). While distinguishing between this type of contact and sex with someone with an "attached, nonremovable" penis is important to assess risk, we wanted to avoid labeling any sex as illegitimate.

The Hit Me Up! Study was approved by the University of Washington Human Subjects Division (#00004760) following the survey and protocol development described in this article.

Results

Sex assigned at birth and gender

Table 1 shows HMU! survey items compared to similar items from NHBS-MSM5. HMU! gender options were from intake forms used at a local peer-run LGBTQ+ health center. Participants were also asked about current, past, or anticipated use of gender-affirming hormones. This question could help avoid misclassification of TGNB participants who identify as "male" or "female" and who were not classified as TGNB through the two-step assessment.

Introduction to sexual behavior questions

The introduction to questions asking about sex partners and sexual behavior was designed to maximize inclusivity and minimize stigmatization of participants, all while trying to assess risk for HIV acquisition:

> "The next set of questions will ask about sexual behavior and injection drug use. … We are not here to judge you…. We know that it may be difficult to answer some of these questions if you or one or more of your sex partners do not identify as male or female, or if you or they are transgender. We also know that how people refer to their genitals can be unique and personal. When we say penis we are referring to only attached, non-removable penises. The following questions may use words that don't perfectly fit how you or your partners refer to your gender or bodies. We are trying to gauge the HIV risk level of individuals enrolled in this study to compare to national and local averages…"

Assessing risk for HIV acquisition

Questions about sex partners and sexual behavior from HMU!, NHBS-MSM5, and HIRI-MSM are shown (Table 2). The HMU! survey assesses sexual behavior by asking only about type of genital contact [e.g., "…how many times did you have receptive anal sex (you were the bottom) with a person with a penis…"] This eliminated the need to label and define sex, sexual behaviors, or sex/gender identity of partners. It captured data that could be under- or unreported using gendered sex behavior questions (e.g., front hole sex with transgender men). Finally, this format led to a shorter survey and reduced the chance of data errors because there was no need to program complex skip patterns.

Table 1. Sex/Gender Identity Questions Used in HMU! and NHBS-MSM5 Surveys

Type	HMU!	Potential answers	NHBS-MSM5	Potential answers
Sex	What was your sex assigned at birth?	Male Female	What was your sex at birth?	Male Female Intersex/ambiguous
Gender	How do you identify your gender?	Male Female Transgender Nonbinary/genderqueer Intersex Something else	Do you consider yourself to be male, female or transgender?	Male Female Transgender
Hormone interest	If you identify other than cis gender, are you currently receiving HRT or gender-affirming hormones or have plans to in the future?	I am currently receiving HRT or gender-affirming hormones I am not currently receiving HRT or gender-affirming hormones, but I have plans to take them I am not currently receiving HRT or gender-affirming hormones and I am unsure if I want to take them I am not currently receiving HRT or gender-affirming hormones and I have no plans to take them I have no interest in HRT or gender-affirming hormones I am cis gender/this is not relevant to me	N/A	N/A

HMU!, Hit Me Up or HIV Prevention for Methamphetamine Users; HRT, hormone replacement therapy; MSM, men who have sex with men; N/A, not applicable; NHBS, National HIV Behavioral Surveillance.

Table 2. Sex Partner and Behavior Questions Used in HMU!, NHBS-MSM5, and HIRI-MSM

Type	HMU!	NHBS-MSM5	HIRI-MSM
Sex partners	In the last 6 months, how many cis men have you had sex with? In the last 6 months, how many trans people have you had sex with?	Have you ever had oral or anal sex with a man? Have you ever had vaginal or anal sex with a woman?	In the last 6 months, how many men have you had sex with?
Receptive anal sex	In the last 6 months, how many times did you have receptive anal sex (you were the bottom) with a person with a penis without a condom?	In the past 3 months, how many times did you have receptive anal with XX, meaning he put his penis in your anus or butt?	In the past 6 months, how many times did you have receptive anal sex (you were the bottom) with a man without a condom?
Insertive anal sex	If you have a penis, in the last 6 months, how many times did you have insertive anal sex (you were the top) without a condom with someone who was HIV-positive?	In the past 3 months, how many times did you have insertive anal sex with XX, meaning you put your penis in his anus or butt?	In the past 6 months, how many times did you have insertive anal sex (you were the top) without a condom with a man who was HIV-positive?

HIRI-MSM, HIV Incidence Risk Index for MSM Score.

By not linking questions about specific behaviors to partner gender, HMU! loses detailed sexual network data. However, the shorter format is sufficient for estimating risk while meeting time requirements.

Other adaptations and resources

In developing the peer navigation intervention, a list of community resources was compiled to support participants, including contact information and descriptions of services for trans-specific organizations providing legal aid, support groups, community building, referrals for trans-competent health care providers, and a 24-h hotline. Other organizations that focus broadly on LGBTQ+ individuals were included for all participants, and recruitment assistance was provided by many of these organizations. Recruitment materials can be found in HMU!'s protocol paper.[8] Finally, texts for the SMS intervention were created to be all-inclusive (e.g., Use the right lube for your hole).

Discussion

In this article, we describe formative work conducted as part of research to evaluate PrEP interventions for individuals who use methamphetamine. Throughout this process, we have wanted to address disparities in PrEP access and research participation. TGNB are often excluded from research, both as participants and as sex partners of research participants. The study team found that adapting cisgender MSM-specific questions to include TGNB participants and partners was feasible and relatively straightforward. The team thus created a survey that met criteria of community advisors and collected needed study data. These data will be presented in a future article.

The two-step assessment of gender is increasingly being recognized as best practice, although variations exist. Some include "intersex" or other nonbinary categories for sex assigned at birth (which will become critical as these options become widely adopted), and others vary for which gender options are listed. Most important is to use nonstigmatizing language that is aligned with terms used in these communities.

HMU! survey questions focused on type of genital contact rather than gender of sex partners, leading to a shorter but more complete survey. Doing so also eliminated assumptions that only cisgender partners are relevant for MSM. One goal of survey development is to balance level of detail and participant burden. While feasible to develop partner-specific questions for every category of sex partner, that specificity was not required for this project. In contrast, studies that aim to fully describe sexual behavior and assess HIV risk must be even more comprehensive to avoid perpetuating disparities among historically excluded populations.

This work has limitations, and additional work is still needed to adapt cisgender MSM interventions for TGNB individuals. Our project involves one population of cisgender MSM and TGNB participants in one metropolitan region. We have not yet developed consensus on how to display, combine, or analyze results of partner gender when multiple permutations result in large numbers of options.[16] Work must also be done to develop a risk score tool that is inclusive of TGNB individuals. While HMU! elected to use the HIRI-MSM, there is no evidence that predictors of HIV acquisition are similar for TGNB individuals and cisgender MSM.

Conclusion

Adapting MSM survey questions for TGNB individuals and including TGNB participants in research is a feasible goal and an ethical imperative. Larger projects (e.g., NHBS, American Men's Internet Survey) should assess TGNB populations to develop validated risk scores for TGNB participants, and NIH should collect data on TGNB research participation to monitor these goals. It is critical that impacted populations are represented among health care and research leadership and paid staff to ensure that surveys and interventions are culturally competent. Failing to do these things will likely lead to persistent stigma, mistrust, and health disparities and an inability to achieve goals of Ending the HIV Epidemic.

Authors' Contributions

All authors had substantial contribution to the work, including conception and study design (V.M.M., J.D.S.), data collection (N.F.), data analysis and interpretation (all), drafting of the article (N.F., J.D.S.), and critical revision of the article (V.M.M., L.R.V., A.M., S.N.G.). All authors have given final approval of the version to be published.

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Author Disclosure Statement

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References

1. Becasen JS, Denard CL, Mullins MM, et al. Estimating the prevalence of HIV and sexual behaviors among the US transgender population: a systematic review and meta-analysis, 2006–2017. Am J Public Health. 2019; 109:e1–e8.
2. Todd K, Peitzmeier SM, Kattari SK, et al. Demographic and behavioral profiles of nonbinary and binary transgender youth. Transgend Health. 2019;4:254–261.
3. Poteat T, Scheim A, Xavier J, et al. Global epidemiology of HIV infection and related syndemics affecting transgender people. J Acquir Immune Defic Syndr. 2016;72 Suppl 3:S210–S219.
4. Centers for Disease Control and Prevention. US Public Health Service: preexposure prophylaxis for the prevention of HIV infection in the United States—2017 Update: a clinical practice guideline. Atlanta, GA, 2018. Available at: https://www.cdc.gov/hiv/pdf/risk/prep/cdc-hiv-prep-guidelines-2017.pdf Accessed August 19, 2020.
5. Zlotorzynska M, Cantu C, Rai R, et al. The annual American men's internet survey of behaviors of men who have sex with men in the United States: 2017 key indicators report. JMIR Public Health Surveill. 2020;6:e16847.
6. Division of HIV Prevention, National Center for HIV, Viral Hepatitis, STD, and TB Prevention, Centers for Disease Control and Prevention. Additional Populations. Atlanta, GA, 2021. Available at: https://www.cdc.gov/hiv/statistics/systems/nhbs/additional-populations.html Accessed August 19, 2020.
7. Centers for Disease Control and Prevention. HIV infection, risk, prevention, and testing behaviors among transgender women—National HIV behavioral surveillance, 7 U.S. Cities, 2019–2020. HIV Surveillance Special Report 27. Atlanta, GA, 2021. Available at: www.cdc.gov/hiv/library/reports/hiv-surveillance.html Accessed May 10, 2021.
8. McMahan VM, Frank N, Buckler S, et al. Protocol development for HMU! (HIV Prevention for Methamphetamine Users), a study of peer navigation and text messaging to promote pre-exposure prophylaxis adherence and persistence among people who use methamphetamine: qualitative focus group and interview study. JMIR Form Res. 2020;4:e18118.
9. Smith DK, Pals SL, Herbst JH, et al. Development of a clinical screening index predictive of incident HIV infection among men who have sex with men in the United States. J Acquir Immune Defic Syndr. 2012;60: 421–427.
10. Stekler JD, Violette LR, Clark HA, et al. Prospective evaluation of HIV testing technologies in a clinical setting: protocol for project DETECT. JMIR Res Protoc. 2020;9:e16332.
11. Kanny D, Adams M, Burnett J, et al. Model surveillance protocol behavioral surveillance team NCHHSTP/DHAP-SE/BCSB contributing authors. Atlanta, GA, 2018. Available at: www.cdc.gov/hiv/statistics/systems/nhbs/operations.html Accessed August 19, 2020.
12. CDC Protocols and Operations. NHBS—operational documents. NHBS Round 5 (2017–2019). Atlanta, GA, 2018. Available at: https://www.cdc.gov/hiv/statistics/systems/nhbs/operations.html Accessed May 7, 2021.
13. Tordoff DM, Morgan J, Dombrowski JC, et al. Increased ascertainment of transgender and non-binary patients using a 2-step versus 1-step gender identity intake question in an STD clinic setting. Sex Transm Dis. 2019;46: 254–259.
14. McMahan VM, Violette LR, Andrasik MP, et al. 'I make sure my doctor doesn't know that I use meth': perceived barriers to pre-exposure prophylaxis (PrEP) uptake among community peer educators in Seattle (WA, USA). Sex Health. 2020;17:29–37.
15. CDC HIV Risk Behaviors. Atlanta, GA 2019. Available at: https://www.cdc.gov/hiv/risk/estimates/riskbehaviors.html Accessed November 3, 2020.
16. McMahan VM, Martin A, Garske L, et al. Development of a targeted educational intervention to increase pre-exposure prophylaxis uptake among cisgender men and transgender individuals who have sex with men and use methamphetamine in Seattle (WA, USA). Sex Health. 139–147. doi: 10.1071/SH18060.

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Abbreviations Used

HIRI = Hit Me Up or HIV Prevention for Methamphetamine Users
HMU! = HIV Prevention for Methamphetamine Users
HRT = hormone replacement therapy
MSM = men who have sex with men
N/A = not applicable
NHBS = National HIV Behavioral Surveillance
PrEP = pre-exposure prophylaxis
TGNB = transgender and gender nonbinary